

HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group

Issue 45 – September 2018

HSP & FSP – Hereditary Spastic Paraplegia,
Familial Spastic Paraplegia & Strumpell-Lorrain Syndrome

Debs had it off for Charity



Debbie and her boss Max, all smiles after Debbie's head shave

I am 56 and have had HSP forever, my brother and a sister also suffer with it. My son has just had the blood tests & sadly is carrying the SPG 4 GENE also. I'm thinking it's about time we had some answers so I've raised £1000.00 for medical research. I don't normally like being centre of attention but to be honest I loved it

because I was doing something very close to my heart and I had my husband's total support. I really didn't realise I had so many friends. On September 11th we set up in the front of the ASDA store in Shoeburyness (where I work) and my boss, Max Scarff, did the honour of shaving my head. It was an amazing experience

and it seems I had a huge crowd all cheering me on. We raised £197.00 that morning and I can say it's the best thing I've ever done. Hopefully some day we will get some answers



Debbie Clark before the head shaving event

I've already raised £1000 for HSP on my Just Giving page which I believe is still up and running so if you want to donate or share amongst your friends, this is the web address: www.justgiving.com/fundraising/debbie-clark25

All the money I raise is for research into HSP and I've donated my hair to The Little Princess Trust, a charity that provides real hair wigs free of charge to children and young people up to the age of 24 that have sadly lost their own hair due to cancer treatment and other illnesses

Debbie Clark

Chairman's Column



I was really pleased with the AGM. It was great to see so many of you there, and I was happy with the group discussions, presentations and positive community feel in the room. Since then it has been a busy time, including starting the process getting us changed to a Charitable Incorporated Organisation. I will update on this as we get more information, and thanks to John and Dave for their hard work dealing with this important activity. Some excellent points were raised in the group discussions, and key points are summarised below.

For those that like to plan ahead the 2019 AGM will remain in the Tally Ho conference centre, and will be on July 13th. I'm happy to hear ideas of what we could do differently this time.

Helping the group

I would also like to hear from anyone interested in helping out with the group. This could either be regular or on an ad hoc basis. At the moment there are three areas where having a few more people to help would be really useful. These areas are:

- Helping with fund-raising. I would like us to make more of sponsored events that people do to raise money for us. It would be good for us to promote these activities more so our profile is raised, and it would be good to have people in high profile events, so there is activity needed to try to get charity places. Several people ask each year about the London Marathon, but this is difficult to get a charity place for. We could look out for the Great North Run, Ride London, and there are marathons, half marathons, 10k's, triathlons and bike rides galore throughout the country throughout the year. And let's not forget sponsored walks, climbs, expeditions and all other activities – long or short, solo or group effort – they all help the group. Help would be useful in coordinating our support for those valuable people taking part in these activities to raise money for us and awareness of the group.
- Attending meetings. There are various rare disease, disability, health and other relevant meetings where it would be good for our group to be represented. The main aspect of this is to make notes of what has been discussed at the meeting to share with members. If you are confident in these situations there is also scope for getting to know other people and groups, and building a network of useful contacts that the group can use. Meetings are frequently during the day and during the working week, and happen all over the country.
- Engagement with younger members. One of the ideas at the AGM was to have representation of the younger viewpoint on the committee. There are a number of ways that this could be done, from occasional input on specific topics through to being a trustee of the charity. I'd be pleased to hear from any younger members, or indeed younger relations of members who might be interested to give their views.

I would be happy to discuss these with anyone who is interested in. Remember, you don't have to be a member to help, but a connection with HSP is useful. So, if you don't fancy this yourself, and you've a family member or friend who you think might fit one of these roles then ask them to drop me a line.

My 2018 Survey

I'm going to use a small part of the newsletter to let you know that my annual on-line survey for people with HSP is now open. I'm repeating my 2013 survey about symptoms and mis-diagnosis, but am also looking at sleep and activities of daily living. I'd be very pleased for you to take part:

<http://hspjourney.blogspot.com/2018/09/2018-survey-open.html>

AGM 2018 Group Discussions

The AGM split into six topics. Each topic sat at a table and there were three rounds of discussions. People were able to change topic between rounds if they wished. The first round was about identifying the most important issues with that topic, and these are described below. The second round was about identifying solutions for those important issues, and the final round was about thinking if the group could implement any of those solutions, and these are also summarised.

Each group discussion had a facilitator to make notes of the discussion and to ensure that everyone had a chance to put their views forward. These excellent facilitators work in/with HSP on a daily basis; Jon Marsden, Cahir O'Kane, Jenny Hirst, Thomas Bourinaris and Emma Baple. They each gave a summary of their groups discussions at the end, and I thank them for helping us on their weekend.

Reducing HSP Barriers

The issues discussed revolved around two key topics – getting out and about, and employment issues. The getting out and about issues covered; changing facilities, access to buildings, hotels and public transport. The areas identified were lack on information about what facilities are available, the logistics of needing to book things and the amount of time/distance to move from one place to another. The employment issue covered provision of support for people still in work and advice on completing PIP assessments. It was identified that there was a lack of information easily available.

Fund-raising

This table discussed several ways of raising money for the group, including: applying to trusts, local authorities and companies. The current style of fundraising was also discussed, with some options for maximising money considered. The discussion noted that it is easier to raise funds if there is a strong story or specific need, and several ideas were put forward for how we could improve this. A need for due diligence was identified for spending funds.

Complex HSP

The key issue for this group was that there is not a lot of information available for those with complex HSP. The discussion revolved around the types of information that was sought, and different ways of improving knowledge sharing.

Key information gaps included: awareness of complex HSP in the medical community, the amount of information for patients, appreciation of the variation in symptoms, severity and overlaps/similarities with other conditions and the rarity of complex HSP. It was acknowledged that some people don't wish to know all the information about their condition.

Young people with HSP

Although there were not many young people with HSP present at the AGM, the group discussed their needs and desires. It was identified that there is a lack of information and awareness about HSP in young people. Overall, this group is seeking more independence and are keen to keep as active as possible, and there is a desire for more positive stories.

Parents of young people with HSP

This group identified key points around lack of information. Gaps included knowing about HSP and research into HSP, knowing about what you are entitled to, how to find out more. There was also discussion around what else should be encouraged, for example activities, and being able to point people in the right direction. It was acknowledged that calling a helpline can be a big deal for some people, and finding out information on the website may be preferable for those people. Communication about HSP with children can also be daunting.

What can the group do for me?

This group discussed a number of things which the group could do. The group recognised that there are many group members who are not on the internet, and we need to consider how we can support them. Topics covered: Sharing information about equipment/experiences, group meetings in new locations, and organising trips/breaks away.

Conclusions:

There are several strong common themes on things the group could/should do from the various ideas put forward by each group. The most frequently mentioned across the groups have been sorted by topic:

Area	Details
Website	Better information: Pointers to other sites/locations, more about specific types of HSP/people, advice/information on various issues. Sharing stories from members about what they have done. Fact sheets for different topics. Research information. Young people section. Make sure information is relevant and focussed.
Mission statement	Having a mission statement helps make our story stronger
Young trustee	Have a young person on the committee
New activities	Fund-raising activities – e.g. coffee morning/HSP day.

	Trips/activities for members, especially young members and isolated members.
Links with others/networking	Create a network of links with other relevant organisations to improve awareness, share information, share tools. Might be charities, research networks, relevant organisations/individuals. Networks might cover specific aspects. Consider hosting network meetings/conferences
Communication channels	Develop non-social-media channels for people to talk. Topics could cover: young people, equipment advice/trading, general chat, etc.
Newsletter	Have a section by/for young members
Fundraising	Have specific projects and seek funding from trusts etc. Define a template/process so this is easier in the future
Promoting our activities	Better publicity around our fund-raising, positive news stories, activities, things we have funded. Make it easier for people to donate. Publicity around our meetings and other events.
Promoting HSP	Famous people with HSP, links with specific people/places/activities/items – media friendly
Research	Being clear about what research we would support. Making information about existing research more accessible. Develop ideas for potential research projects
Lobbying	Raising awareness of HSP and associated issues with: MPs/Local authorities/transport bodies/companies
Non-internet support	Ensure that we're supporting those who don't have access to internet. Could consider funding internet access for these people?

Adam Lawrence

Editor's Column

Since I completed the last newsletter I have taken up a couple of interesting activities. I'm doing less flying these days mainly on account of mobility and fatigue issues and the horse riding I've enjoyed for so long is on hold while a new venue is sourced, so I felt I needed some new hobbies. I'm a great believer in keeping busy or it could become far too easy to spend too many hours sat in a chair feeling low.

A local radio station called Forest FM interviewed me at the Potato Pants Music Festival on June 1st and as a result of that I am now one of their DJ's. I have a show on Friday evenings called 'Wired' where I highlight our amazing music in Dorset and Hampshire. I was thrown in at the deep end and took a few weeks to get used to it but I'm now really enjoying it. This has made it necessary for me to go out to more concerts and gigs looking for more talented musicians, which is something I've always enjoyed doing. I've met loads of

lovely people already and a great perk is that it'll help me find more musicians for next year's Potato Pants Festival. If you fancy a listen, tune in to Forest FM 92.3FM on a Friday evening at 8pm.

As many of you will know, I've been involved with another amazing charity for several years, called Flying Scholarships for Disabled People. Since I was awarded a Flying Scholarship in 2005, through spreading the word, about a dozen of our members have now been through the same amazing aviation experience. This year two more of our members have been awarded Flying Scholarships and by the time you read this they will either be enjoying the flight training or have just completed it. Congratulations to Tracey Aggett and Tim Matthews. Tracey was awarded a flying scholarship at Kemble airfield and Tim's flight training was at Turweston aerodrome near Silverstone. Each scholarship costs over £10,000, so FSDP have

now spent well over £100,000 on HSP members. I'm very proud to be involved and hope that Tracey and Tim had, or are having amazing experiences.

Having read the above, I'm sure you'll now appreciate why I've entered the Bournemouth Half Marathon, raising funds for Flying Scholarships for Disabled People. I ran it in 1990 and on October 7th, 28 years later, I'll be doing it on my wheelchair. I've been training very hard, which has been surprisingly enjoyable and I've definitely noticed an improvement in my every day wellbeing. I have a fundraising page on VirginMoneyGiving. Many thanks to those who have already donated, it's an amazing cause that can completely change the life for the better of disabled individuals, as a number of our members have now discovered.

I'm already busy making plans for the next Potato Pants Festival and the exciting news is that the venue will be changing for 2019. I've found a much more accessible site with good disabled facilities. Fingers crossed that in 2019, it'll be bigger and better than in the previous years. Full details of the new location will be in the next newsletter.

Ian Bennett

Intrathecal Baclofen Pump

Like many more of you, I used to take Oral Baclofen, 70mgs per day, this being 20mgs at morning, 20mgs mid-day and 30mgs at night time.

In December 2013, I went into hospital to have my Baclofen Pump fitted and I will never look back.

Before the operation could be done, they tested by injecting the Baclofen into my spine to see if it was going to be beneficial and if so they could then do the operation.

For the test I had to go into hospital. They had me walk 10 metres and noted how long it took me to walk that distance and how many steps it took, this was done before the Baclofen was injected into my spine.

Then, whilst laying down, they injected 25mcgs of Baclofen into my spine and I had to

lay flat for one hour, when they then had me do this process again.

They usually start with a low dose of 25mcgs to see if it has any effect, but in my case, they didn't notice any change. With also being Epileptic I had to stay in hospital for the night as my Neurosurgeon told me that Baclofen taken intrathecally could trigger off a seizure, this going against my Epilepsy medication and neither of us wanted this to happen, especially when the Epilepsy has been controlled with medication for many years.

Before I left the hospital the following day, they asked me to come back the following week and have the same test and treatment but this time using 35mcgs. This time they did notice a difference so I was then told they could go forward with the operation. The most that they test with is 75mcgs and if this doesn't work then they will not operate.

Since the Pump was fitted, I now get 50mcgs per day and I have noticed a huge difference. It's hard to believe when I was taking Baclofen orally, I was on 70mgs per day, (which equates to 70,000mcgs), that such a small amount could actually work, but it did.

The Pump transports the Baclofen through two catheters, one through the front of my body and the other through my back transporting the Baclofen straight to my legs so I am nowhere near as sleepy as I was taking the tablets.

The Pump comes in two sizes, 40ml used for adults and 20ml for children. With this being the first time for me the consultant fitted and filled the 40ml Pump.

I usually go every three to four months for it refilling and the first time I went back I had only used 16mls so the remaining 24mls was then taken out and had to be disposed of, as with any medication, it loses its strength after a while and will not work to the best of its ability. He now just puts 20mls in, I still use approximately 16mls so there is very little waste.

With the preparation, the refilling is quite an easy process as the Pump has a silicone button that the needle enters to take out the

old and put in the new and this takes approximately half an hour to complete.

I have this done without any anaesthetic so that once it has been done I can go straight home and not have to wait until I feel safe enough to leave the hospital. I didn't get asked if I wanted any anaesthetic, he just went ahead and did it. It was a bit scary the first time but now it doesn't bother me.

The Pump is computerised so the dosage can be altered as and when, but I have to go to the hospital for this to be done.

To do this, all the consultant does is ask me to hold a machine on the Pump and all my details show up on the screen he is holding, he then taps in to amend the details and this then shows the new dosage.

Once this has been done, the dosage in the catheter will change and within a minute or so I am getting the new dosage.

There are two different sounding alarms in the pump:

1. When the pump is **"nearly empty"**, I have to get in touch with the hospital to make an appointment to go in to get it refilled, and
2. When the pump is **"empty"**, I have to go straight to the hospital and they will contact my Neurosurgeon to come and do this as soon as he can.

Thankfully, neither of these have happened to me so even I don't know what they sound like, but I often wonder what others would think if they heard this, *ha ha ha ha*.

The Pump has a lifespan of approximately seven years so I only have a couple of years to go until mine is replaced.

I was chatting with another of my Consultants about the Pump and when he told me the cost I was shocked. The whole thing is £17,000, this being £13,000 for the Pump and two catheters which are £2,000 each, *(he just said "you deserve it")*.

Thankfully, I got this done on the NHS and I hope things will stay that way.

If anyone would like to chat about anything that I have spoken about, then I will be more than happy to help where I can.

My details are:-

Mobile No. : 07944 483 498

Land Line. : 0113 230 2093

Email. : deborahbest@btinternet.com

For anyone using Facebook, I am also on the two groups we have there, i.e.

- **Hereditary Spastic Paraplegia's Unite, and**
- **Hereditary Spastic Paraplegia Support for UK HSP'rs**

(Don't be afraid to use these as both of them are **"Closed Groups"**, so can only be seen by the Members)

REMEMBER!!

"Were all in this together"

Deborah Best (Debs)

My Hemp Oil Miracle

I began to have excruciating pains at the top of my leg, in the groin area & didn't have a clue why I should suddenly be having them. I would be stood up with my Zimmer Frame & my leg would suddenly shoot up from the knee & lock into that position. It would randomly happen as I was sat down as well & it always brought me to tears. I was having very little sleep because it was happening in bed during the night also. I saw my Specialist who gave me an x-ray, it was even a struggle to lay there to have the x-ray, my leg just could not tolerate me laying still. I even had a MRI Scan which was just impossible, I tried to lay there with someone trying to hold my legs still. I had to lay for a good 20 mins, oh the pain was just impossible to cope with, they could not get a proper reading, as my leg just hurt & moved about for the majority of the time. I spent nearly 3 weeks in Hospital having treatment after the Specialists diagnosis, I basically had to have a Enema every morning & laxatives every day. It was terrible & I can't even begin to tell you just how physically & mentally messed up I was, I was also put on Gabapentin every day & evening to aid the pain along with Clonazepam just in the evening, so I could get some sleep.

Well basically, I was sent home after another x-ray, with the Specialist saying he had done all he could, confident I would be free from the pain now. Within a day the pain returned which was just as excruciating, I had to go to Accident & Emergency twice because I was in such a state. I had gone through a whole canister of Gas & Air, put on a drip with Paracetamol & something else added to it. Lastly I was given Morphine & still the pain would not go, the Hospital said I must go back to my Specialist, which I did so. He told me he did not have a clue what was causing it, he told me he had 350 odd patients on Baclofen. He had initially put me on Baclofen, which I could not tolerate, now I was dosed up with Gabapentin & Clonazepam which had just made me so sleepy for the majority of the time. Still though the pain was attacking me, so I was so sleepy, forever tearful with the pain, this was my life every day. It was very rare that I could get up & sit at the table to have tea, or to sit & watch tv comfortably.

My Miracle happened the day my daughter Natalie came to my house with some Hemp Oil, she put 5 drops into my mouth under the tongue & told me to leave it there for a minute before swallowing. Well guys I was absolutely flabbergasted, within an hour my leg had a relaxed tension about it, I was just in so much shock & relief!!

We all know that HSP targets the Muscles & we have had talks at the AGM Meetings from experts about Peristeen for Constipation. Well I did not waste time in getting one for my toileting needs, which I remember sharing with you all in an article, because it had made such a difference to my life. Well I was silly enough not to carry on using Peristeen after a lady talked me into using another System called Braun. It only just occurred to me the other day that it was this change that I had made had been the contributory factor of the pain. I had been using it every day, but the Specialist had said I was excessively constipated, the Braun I feel hadn't worked as effectively as the Peristeen. I have since been back to see this same Specialist & he was absolutely overjoyed with what I told him about this amazing Hempworx Oil. He told me he has never seen anyone suffer as I had

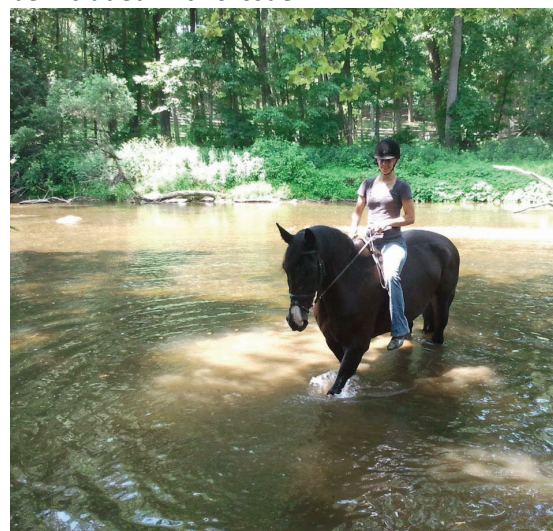
in all of his 350 odd patients, and asked if he could put anyone in touch with me if they had the same suffering as I'd had.

I have slowly weaned myself off Gabapentin & Clonazepam, I still take the Hempworx Oil, but not every day. I also have gone back to using Peristeen. I feel a different person now, I feel happy, my head is just functioning so much better now & I have recently got myself back to the Gym. Obviously I have struggled so much that I've become a lot weaker in my legs. I will keep on battling to manage HSP, and not let HSP manage me.

Christine Snow

Lovely Words from Paralympian Rebecca Hart

Rebecca Hart featured on the front page of a previous issue of Newslink and I saw these lovely words on Facebook and felt they should be included in this issue.



I don't really have the words fit to describe this horse. Beckon came to me 20 years ago, when I was 13. He has been a friend and confidant ever since. He was a jack of all trades, with less than perfect conformation. He didn't win any titles or championships that would deem him a great horse by the normal standards, but he was great. He came to me when I needed him most. I was an angry and broken disabled kid trying to come to terms with my version of "normal," a normal I didn't like. I felt trapped in a body I couldn't control and judged with the world's label of disabled, but horses don't have prejudices. He didn't

see me as disabled; he just saw me as his girl... “strange girl” with a dragging footstep that meant cookies.

He was a patient old soul and allowed me to make mistakes. We had adventures and mishaps, but most importantly we had fun. He let me change the anger I had and turn it into a passion for horses and sport. He opened me up to a world that would forever change the direction of my life. What is often a “phase” in a girl’s life became a platform for me. I will forever be grateful to this horse for opening my eyes and allowing me to see that being unusual was ok; because when unusual meets normal...extraordinary can happen. I will love you forever black horse.

Rebecca Hart – USA Paralympian

Since including the above from Rebecca in the newsletter, I’ve discovered that she’s won a silver and bronze medal in the World Equestrian Championships. Congratulations Rebecca from all of us in the UK.

Fundraising News

Easyfundraising

Since I publicised [Easyfundraising.org.uk](https://www.easyfundraising.org.uk) at our AGM we now have 27 individuals raising funds for us using this facility and we have already raised over £75.00. If we can attract more people to get involved, this could add up to serious money. If you ever shop online and are interested in supporting the HSP charity, please get in touch, it's so easy to do. There is no catch, it really is a no brainer. For example, every time we do our supermarket shop online with Sainsbury's, 50p goes to HSP and other retailers pay us up to 3% of the value of your purchase. We’ve just renewed an insurance policy on a car and if we’d realized that if we’d navigated to the insurers website, via the easyfundraising site, £10 would have been donated to the HSP Group.

There are thousands of retailers who support this including Amazon, Groupon and Ebay, not to mention most high street stores. Use the following link and follow instructions:

<https://www.easyfundraising.org.uk/causes/hspsupportgroup1/>

As I said, any problems, give me a call but it’s proving to be a great way of raising funds, we simply need to get more members and friends involved, and it really is quite simple.

Raise 5p/mile with fit4change

If you know anyone who does a lot of walking or running, they can earn 5pence/mile for HSP. I use it myself when training for the half marathon on my wheelchair and I just say I’m doing a run. It’s very simple, all you need to do is download the Fit4Change App and make sure you have your phone on you and WiFi/mobile-data on when doing the activity. GPS technology monitors the distance completed and the money your activity raises is paid from the advertising revenue generated by the Fit4Change App. The App is available from: <http://www.fit4change.com/>

The infographic is set against a red background. It features four numbered steps in blue triangles at the top. Step 1 shows the app on the App Store and Google Play. Step 2 shows the app interface with a person walking. Step 3 shows the app interface with a person walking and a red circle around the 'Start Fundraising' button. Step 4 shows a silhouette of a person in a wheelchair. Below the steps, the text 'Four simple steps to healthy fundraising!' is written in white. At the bottom, there are logos for 'fit4change' and 'The Hereditary Spastic Paraplegia Support Group'.

So far I’ve done 150 miles in training for the half marathon and raised £7-50. Some may say it’s a lot of work for £7-50, but I was doing the training anyway. If we could get a number of members and friends using this App, even if it’s simply when they walk the dog, the money would add up. If members have friends who are runners, please pass this information on. Anyone can raise funds for HSP using this facility and it’s very simple to use.

Tesco – Bags of Help

Bags of Help is Tesco's exciting local community grant scheme where the money raised by the sale of carrier bags is being used to fund thousands of local projects in communities right across the UK. Projects that bring benefit to their community will get the green light – these range from improving community buildings and outdoor spaces to buying new equipment, training coaches or volunteers and hosting community events.

Following a carefully worded application, the HSP Support Group is one of the three charities that Tesco in Blandford, Dorset are currently supporting in their Bags of Help scheme. We will either get £1000, £2000 or £4000. I visited the store recently to check how we're doing and we seemed to have as many counters in our pot as the competition.

Thanks to our fundraisers

Several members and friends have been busy fundraising for us recently. I'm not going to try to remember every activity but I'd like to mention and thank the following.

I'll begin with my daughter Jade who raised money for the HSP Support Group by running the London Marathon. Not only did she raise significant funds but she was also responsible for inspiring me to do the half marathon in my wheelchair which I mentioned earlier.

You've already read Debbie Clark's story and how she was brave enough to have her head shaved for us and has raised around £1000 for us in the process.

Will Watson who featured on the front of the last newsletter has raised over £200 by climbing five gruelling peaks in the Himalayan mountain range.

Elsbeth and Gordon Strang, together with two friends, have raised over £700 for us by running the Skye half marathon which you'll read about in the next article.

Carole Jakeman raised money for us by asking for donations instead of birthday presents for her 50th birthday.

Martin King-Davies raised money for us by asking for donations instead of birthday

presents for his 60th birthday and silver wedding anniversary.

The above are just some of the individuals who've raised funds for us in the past twelve months and on behalf of everyone involved with our organisation, I'd like to thank them and everyone else who's been involved with fundraising for HSP.

Ian Bennett

Skye Half Marathon for the HSP Support Group

In June 2018 our team of four made the journey to the Inner Hebrides to run in the Skye Half Marathon for HSP Support Group. The team consisted of Naomi Mervin, Elspeth Strang, Maeve Ryan, and Gordon Strang. Two of us were running our first half marathon, and two of us were going for our second. We joined forces to compete in one of the hilliest half marathon races in the UK.

Elsbeth and I had a personal reason to run to raise funds for the Support Group. Our cousin was diagnosed with HSP aged 19 and is a total hero dealing with it but life is tough. We believe the work of the group to assist research and support members is incredibly valuable.



Gordon, Maeve, Elspeth and Naomi with their medals after completing the Skye Half Marathon

On Saturday the 9th June we lined up on a hot day for the start of the race. After a dancercise warm up we were piped to the start line by the Portree pipe band. The Skye half marathon has made huge strides in the last few years, going from 400 runners, to 600, and up to 1000 runners this year. The

route had been reversed this year, and began with a 3 mile uphill stretch. The effort of the uphill sections wasn't matched by the ease of the downhill, and it was certainly a tough race. Nevertheless we were spurred on by fantastic community support, such as the primary school handing out water, and we all completed the run.

A special mention must go to Naomi for coming in as the fastest woman aged 26, and to Elspeth for being the fastest of our group. Also congratulations to Maeve for completing a personal best time.

The day was finished with a ceilidh at the Portree Shinty Club, where our legs were tested for a second time. We then enjoyed a few more days on Skye, a wonderful place to visit despite the burgeoning midge population.

Our current fundraising total is £770, which we are delighted with and we would like to thank all of our supporters for their thoughts and generosity.

We would like to thank the organisers of the Skye Half Marathon for putting on such a smoothly managed race with a community atmosphere.

Gordon Strang

The Facebook HSP support sites are doing well

The Hereditary Spastic Paraplegia's Unite group has over 1900 members from the UK and around the world, connecting HSP'rs to people who could 'understand'. Finding that no matter where we are in the world, information and management on living with & maintenance of HSP is basically the same.

Earlier this year I started a UK only Facebook group called 'Hereditary Spastic Paraplegia Support for UK HSP'rs'. This group is also doing well, with about 255 members. A different, if not alternative to the worldwide group. Concentrating on UK help & advice/support. For members who prefer not to give details of their particular HSP journey to the outside world. Many are members of both groups, as I am.

We appreciate that members are worried about the internet because of scams/security etc. The admin teams on both of these groups do their very best to monitor & act in the best interests of the members, keeping the groups 'closed'. Which means only members of those groups can see what is written etc. It is up to the individual member whether or not they want to interact or answer questions/friend requests/private messaging from anyone in the group or on their page. There are security settings to control which information they wish others to see or who they allow to contact them.

There are a lot of members that are quiet and just observe what is written/posted/commented on. They can learn a lot by just doing that. Others are more active with the input on the group page and have developed friendships through the closed sites.

We hope to welcome you to the HSP Facebook groups. There is a picture of members that attended the HSP Support Group UK's AGM 2018, which you will see when searching for the groups.

Thank you.

Della Brookman.

David Pearce



It was with much sadness that we recently learnt of the death of our former Chairman David Pearce.

David was chairman of the HSP Group when I joined in 2003. He was very enthusiastic about the future of the Group and I know he'd

be delighted about the way things have moved forward. He loved speaking to members as chairman and always did it with a big smile on his face. David, with Ian Smith, initiated the Regional Meetings at the AGM in 2000. Sally Langton had identified areas, and for each, when possible, a coordinator/facilitator was identified. The meetings were to be held regionally but were not to be dedicated to the specific members; all were welcome. He helped with getting the West Country Group together and he attended the first two meetings in Exeter. He regularly attended the Milford meetings until illness and mobility issues got the better of him.

David had a very good working relationship with the treasurer Mike Fawcett and between the two of them, organised all AGM's and went to a lot of trouble finding suitable venues. Sadly, Mike passed away a few years ago.

David was always thinking ahead and how the group should grow.

Since the news of David's death, we have received many emails from members sharing lovely words and memories of him. It is clear that he will be dearly missed.

We'll never be able to thank him enough for all he did for our HSP community. Rest in Peace David

Ian Bennett

I worked with David from when he came to the group in 2003 until Ian took over from him. I was already doing the helpline as I joined in 1987 when there were 5 of us in total in the group. David was always full of enthusiasm which never wavered, he always felt very fortunate that he suffered no pain with the condition. I will miss his positivity for the group which he felt was his life saver.

Stephanie Flower

I was sad to hear a few week ago about the passing of David Pearce.

When I first joined the Group in 2005 he was the then Chairman and I first met him at the

meeting in Peterborough and was made really welcome.

David and the then Treasurer Mike Fawcett, who we lost a few years ago worked hard to make the meetings viable.

A few years ago David stood down as Chairman to make way for "younger blood", that's when we voted Ian Bennett (Ben to a lot of people) to be the Chairman who again did a wonderful job until a couple of years ago when he stood down and Adam Lawrence took the seat as Chairman to enable Ian to be able to put his all into being the Membership Secretary and Newslink editor.

In the last few years David became unwell for other reasons than HSP, he did tell me I could let the Group know on his behalf that he had Pancreatic Cancer and Diabetes, as if HSP isn't enough on its own.

I used to ring him a couple of times a week to see how he was doing and he always asked about the Group and how things were going and he was happy to hear about the progression of the Group and was sorry that he was no longer able to join us all.

He did try when he could to attend the Milford Meeting, organised by Jane Bennett but in the end that got too much for him too.

I, like a lot of you will be glad to hear that he is no longer suffering and Mike and him are back together again at peace.

RIP David – 2018.

Debbie Best

Brian Walker

It was with great sadness when we learnt of the death of one of our young members from Dorset.

Brian Walker sadly passed away in December last year. He was affected by SPG11 and very bravely got on with his life, ignoring constant pain.

Originally from Watford, Brian and his parents moved to the Christchurch area in 2017.

I remember chatting to him at a Milford meeting and having a giggle about football. He was an avid Tottenham supporter and I teased him, saying they'd never beat Bournemouth. I remember that Brian found this very amusing.

Brian is very sadly missed by his mum and dad, Jean and Fred, and mum continues to be a member of the HSP Support Group.

Ian Bennett

Sir Ian Denholm

Sir Ian Denholm passed away on 15th May, a week after his 91st birthday. He had suffered from HSP from the age of about 46.

Sir Ian was involved in ship management and in 1989 he was knighted for his services to shipping following a term as President of the UK Chamber of Shipping.

His family and friends admired him enormously the way he coped with his diagnosis, he was totally positive and although the increasing paralysis meant he had to give up the sports he particularly enjoyed, he never complained about this, merely turning his attention to other things that he could still do, taking on these new hobbies as a challenge (latterly playing chess on the internet with his grandson and great-grandson).

He continued to travel widely for business and holidays until his late 70's, finding to his surprise, in many ways it was easier travelling in a wheelchair, as he got such excellent help at airports, than it was when he travelled on foot. There were of course exceptions!

Sir Ian felt lucky that there are now such excellent aids and equipment to make life much easier than it had been for his father when he too had to battle with HSP. He appreciated his excellent OT who was always interested in new devices that were coming on the market.

Although the diagnosis of HSP changed his life forever, it never defined him.

Ian Bennett & John Mason

Trip to Whitby

It was glorious weather and my train journey took me through Middlesbrough so I wasn't expecting much.

From Middlesbrough to Whitby though is across the North Yorkshire Moors and there is not much sign of life except the cows grazing and sheep chewing the grass. There was a burst of life when we stopped at Grosmont which is also a stop for the North York Moors private railway where there are all sorts of railway coaches from Pullman dining cars to ordinary railway carriages.

Looking at the map most stations are not near the village they serve which explains why people got on and off in what seemed the middle of nowhere. Explorer Capt Cook and Endeavour are prominent in the area as he came from the area and the ship sailed from Whitby.

We continued along the River Esk valley to Whitby crossing many bridges on the way through deep valleys and green slopes as we followed the flowing river alongside with views across to distant moors. This went on for 2 hours of single track and village names where people got on and off. A lady I got talking to said the council uses the train to take children to school so the train is contracted to run. Glaisdale is an example of how the train follows the river so stations are not near the village which tend to be on high ground

Foxgloves and other colours mixed with the many greens and gold as they mixed with the blue skies and white clouds and all seen through a train window where cars can't roam.

As our regular diesel train stopped at Whitby it was alongside the North Yorkshire Moors train that provides a regular service from Whitby to Grosmont and Pickering. It seemed quite frequent and alternated between steam and diesel locos. There are also special trains that serve lunch, tea, dinner.

Whitby is a small fishing village that has grown to a seaside resort. It is a host of narrow lanes. The harbour is full of boats that give trips as well as those private boats.

I was in Whitby because I had been invited to a boat naming ceremony by WetWheels Yorkshire. This was a boat adapted for wheelchairs and limited mobility people. It was being named by HRH Princess Anne. The boat can take three wheelchairs firmly strapped in and 11 others. As it goes out to sea it revs up like a speedboat as the sea permits. Each person gets an opportunity to 'drive' the boat. It is funded by charity and fees for trips and most of the boat people are volunteers. You can see a video at

<https://www.youtube.com/watch?v=FhtIf50UIF8>

The town is famous for its fresh fish and cafes are all around. The sun added to the glorious day but the steep hills might give a

spectacular view but they are a bit beyond HSP's (Round Town Bus??)

Mike Cain

HSP Group Grants

Funds are available for members to apply for financial assistance with the purchase of mobility aids or equipment that may improve quality of life or simply make life easier. The maximum grant available is currently £750. Completion of one year's membership is a requirement for applicants. If interested, please request a grant application form from a committee member.

Forthcoming Events

Norwich Meeting

Saturday October 6th 2pm
Meadow Way Chapel NR6 5NU
Call Barbara Jones on: 01603 423 267

Birmingham Meeting

Saturday October 13th midday – 3pm
The Kenrick Centre, Mill Farm Rd, Harborne, Birmingham. B17 0Qx
Contact Penny Cohen on 07818 288 738
Or June Masding on 07500 584 681

Ashburton Gathering

Saturday October 13th 2pm onwards
The Dartmoor Lodge Hotel
Peartree Cross
Ashburton
Newton Abbot
TQ13 7JW
Call Ian Bennett on: 01202 849 391

Milford Afternoon Tea South/South East

Sunday November 11th 3pm – 6pm
The Clockhouse
Milford
GU8 5EZ
Call Jane Bennett on: 020 8853 4089

Colchester Meeting

Sunday, October 14th 2.30 - 5pm
Feering Community Centre
Feering
Essex
CO5 9QB
"We are hoping to be joined by a Falls Prevention officer from Colchester to advise us on preventing and getting up from falls."
Call Hilary Croydon: 01284 728 242
tohiti@btinternet.com

Stockport Meeting

Saturday 29th September 2pm – 5pm
Quaker Meeting House
2 Cooper Street
Stockport, SK1 3DW
(For sat Nav use: SK1 3QL)
Call Irena Pritchard: 01524 261 076 or
Mike Cain: 01614 567 531
irena.pritchard@btinternet.com

HSP Support Group AGM

Saturday 13th July 2019 10 am – 4-30 pm
Tally Ho Conference Centre
Persore Road
Birmingham
B5 7RN

New Members

We welcome the following new members:

Anne Taylor Ashford	David Taylor Poole	Robert Hodge Preston
Anthony Stephen Harlow	Elaine Kirkham Cheshire	Sally-Ann Spooner Walsall
Ben Goler Huddersfield	Martin Warden Felixstowe	Julie Anna Malkin Barnsley
Rachel Mortimer Holdsworth Cambridge		

If you are interested in contacting any of the above new members, please contact the membership secretary.

Summary of 2018 AGM Presentations

A carers perspective of HSP, Pat Reed

The first presentation of the AGM was one of the groups members, Pat Reed, giving us a carers perspective of HSP. Pats husband, Terry, has HSP, diagnosed in the early 1990's. He was additionally diagnosed with Parkinson's in the mid to late 2000's. This is Pats story.

Pat described their initial journey with HSP, starting to use walking aids and then making decisions at each stage as the needs change and using more and different aids. Additionally, they had an increasing need to plan toilet stops into journeys. The Parkinson's diagnosis came at about the same time as the move towards needing a wheelchair. The combination of HSP and Parkinson's is rare, and this is coming from the perspective that HSP is rare in itself.

The journey towards being a carer is slow, like the journey with HSP and its symptoms. In the early stages you don't consider yourself to be a carer, but as the HSP and the Parkinsons takes away the person that you love, that relationship changes into carer and cared for. As the changes are gradual there isn't a specific point when this switch happens, and that doesn't stop you from loving that person.

There is a large amount of team-work involved in this relationship, and the problems are always the conditions, never the person. Solutions are found which work, and these are developed over time as the symptoms change. At the moment, fatigue is key, with energy levels dropping it is a time to make difficult choices about what to stop doing, and what to keep on doing. Difficult decisions to be made when you enjoy and have passion for doing these things.

As a carer, as the condition changes and the need for caring increases, it is necessary to give up your own interests so that you put your energy into ensuring that your loved one can carry on going for as long as possible.

With two conditions, there is a lot of medication to be taken over a 17 hour period each day. There are alarms and reminders, and the medication interferes with the lack of energy and the ability to have flexibility in your routine. Money has been spent on modifications at home, with lifts, wet rooms, ramps and wider doors. The caring routine includes helping getting dressed, helping getting in and out of bed, helping going to the toilet and helping transfer to a wheelchair.

A range of different specialists have been seen, including occupational therapists, neuro-physiotherapists, and staff at a MS/Neuro centre. Each has been able to offer their help, but for limited times, and the changes to health conditions mean that it is not possible to get to the centre any longer. There have also been various visits to hospital, A&E, but also advice to avoid going to hospitals if possible. This means a further change in the relationship, from carer, to carer and nurse.

The tricky question is - what happens when something happens to the carer? One incident meant that the caring routine was disrupted by dizziness and sickness, such that the bare minimum was done, before getting back to bed to start recovery. In this case, there wasn't any home care available to offer respite during the recovery, so they ended up for a short stay in a care home.

After this, care was organised for two nights a week, offering some respite, but also some guilt, knowing that your loved one is not getting the respite that you are. Having visitors in your home right at the end of the day also means a change to the usual routines.

Being a carer needs you to be strong. It can also be lonely. The strength is needed to change the routines or the medication when you can see that the dis-benefits are significant and don't balance with the benefits. The strength example was a new medication which helped with sleep at night, but also didn't allow for getting things done during the day. The lonely example was the story of having to clean up after not getting to the toilet in time. Some planning is needed so the right things are in the right place at the right time, and a sense of humour and positive attitude are both essential.

The story concluded with a look back from the early days, when trying to get on the Eurostar. Some unsteadiness on the escalator meant they both ended falling over on their way up the escalator. Some other passengers helped to get the upright, but that hadn't stopped their luggage ending up back at the bottom, with no downward escalator. They were taken by the station staff, with their luggage, to the correct point on the platform to get on the train for their seats, and away they went!

An overview of Occupational Therapy - Fiona Shea

The second presentation of the AGM was Fiona Shea, who is an occupational therapist. She gave an overview of occupational therapy.

Essentially an occupational therapist helps people achieve their aim. This might be by resolving physical issues, by looking at the person and the environment they live in, by looking at rehabilitation or posture. The practice is both generalised and specialised. Fiona noted that the physical issues that she resolved are not always physical issues, often she helps those with mental illness.

Occupational therapy works in a simple four stage process. The first stage is to assess the situation. The second stage is intervention planning, followed by the third stage of putting the intervention(s) in place. The final stage is to evaluate the intervention. The evaluation

may show a need to re-assess and re-plan interventions, or if the intervention has been successful the patient would be discharged.

The assessment stage looks at the person and identifies what they are having issues with. Fiona described a model which is used by occupational therapists to show the inter-relation between the person, their occupation and their environment.

When interventions are being planned they can sometimes be small, and other times they can be longer term objectives, built up at an appropriate speed. The goal of the intervention must be smart (specific, measurable, achievable, relevant, and time-bound.) If the patient has accepted their condition/situation then this can make intervention planning easier.

Once the intervention has been planned, if it involves behaviour change then it is up to the patient to put this into place. If the person is not bothered by the issue then the goal has not been set right.

The evaluation stage becomes assessing if the goals have been met. If not, a re-assessment or re-setting of the goal may be in order. If the goal has been met then there is a need to look to the future to consider what may happen going forward before being discharged.

Functional Electrical Stimulation - Jon Graham

The final presentation at the AGM was an ad-hoc presentation by Jon Graham of Physiofunction (<https://www.physiofunction.co.uk/>).

Jon described that Functional Electrical Stimulation (or FES for short) was part of a rehabilitation triad that they use at physiofunction. The three elements of the triad are Physiotherapy, Exercise and Technology.

Where there is a muscle imbalance the FES system stimulates the nerve, this fires the muscle and causes it to move. The FES systems are usually positioned so that they lift the foot up when stimulated, often making it lift quicker than it would without the FES. The level of stimulation can be varied over time, as patterns in your gait change, and so that you prevent system over-loads.

The main centres for FES in the UK are Birmingham and Salisbury, and two of the main equipment manufacturers are Bioness (<https://www.bioness.com/Home.php>) and DM Orthotics, or DMO (<https://www.dmorthotics.com/>). Jon noted that traditionally FES is provided by a unit which straps round your leg, the technology is moving on and it is becoming incorporated into a sock or membrane. You can get whole body systems, such as the Mollii suit (<http://www.remotion.co.uk/>) which instead of having a few pads like the strap-on system can have between 45 and 50 pads.

There are four routes to getting FES on the NHS. Some regions have a commissioning service. You may be able to register as an "exceptional case". You may be able to regard FES as a mobility aid and get this through the back to work scheme, or you can go through a private channel.

NICE note that FES can be used to help footdrop of central neurological origin (<https://www.nice.org.uk/guidance/ipg278>) - which would include HSP.

FES can be used to help build muscles by use with FES Cycling, where the FES system helps you to pedal a stationary bike, and the pedalling helps build your muscles up again.

Jon concluded by mentioning the National Footdrop Society (<https://www.nationalfootdropsociety.com/>)

Adam Lawrence

Useful Contacts

	Email	Telephone No:
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John Mason - Treasurer 18 Sandringham Road, Trowbridge, BA14 0JU	john@jrmason.demon.co.uk	01225 761 788
Stephanie Flower - Help-Line 37 Alexandra Road, Great Wakering, Southend, SS3 0HN	stephanyflower@gmail.com	01702 218 184
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